The Journey to Care – reflections of a service user

In 1996, I experienced a life changing moment at the age of 68. As an engineer, and sporty person, the onset of a series of unexpected and unusually frequent falls was troubling. Matters became really serious when I discovered that I was unable to rise unaided from the floor. Having resorted to mechanical aids to assist in getting to a standing position, I was referred to a neurological consultant. In effect, the annual appointments became nothing more than a monitoring of my physical deterioration. A fall at home in 2013 proved significant. The eventual diagnosis of an untreatable neurological condition, which causes muscle deterioration, resulted in my move "into another world."

Government rhetoric centres on the language of 'compassionate care, personalisation and informed choice' (Care Act 2014, Conservative manifesto 2015, Department of Health and Social Care 2006), however, the lived experience continues to reflect a differing story.

Choice? What Choice?

I have been at my current placement for 4 years. However, the journey to here was reflective of the numerous transitions experienced by some children in the looked after system. From home I was sent to the only available bed, which was in a 40 bed dementia unit, for 5 days. This first entry into "care" can only be described as a "nightmare" that has scarred me deeply psychologically. Left alone in a darkened, shared room unable to independently move, with no consideration or attention given to my emotional needs, was scary and intimidating. Following this stay for 5 days I experienced considerable instability in my care; a period at a community hospital, moves to other residential units and so on. Choice was limited to what was available and was not always an informed one. On reflection, in such situations choices are made by others, often in moments of stress and in difficult circumstances. This process offered little choice, or indeed consultation with myself. It was disempowering and instilled an emerging feeling that I was now considered worthless to society.

The psychological impact of diagnosis, let alone this move into "another world" of hospitals and residential institutions, was devastating. I was no longer part of society, but part of a socially isolated world; the invisible community of residential care.

Alongside the physical, emotional and psychological adjustments I was faced with, the issue of financing my care became a pertinent issue. The Health and Social Care Act 2001 section 55 meant Local Authorities were empowered to operate deferred payment schemes (where people could defer payment for care) and were given powers to make a loan to a resident and recover the money from the person's estate by putting a charge on their property. This allowed people in residential care to defer paying their charges until they were able to sell their house, but often meant that the costs of care were only recouped from house sales after a person's death. For me this reality is reflected in the £29 allocated to me a week. The law has allowed a "money grabbing system" to emerge. Additionally, with the increased need to depend on others to make decisions on my behalf; my life has been "torn apart." Along the way I had some good social workers who fought my corner, fought the bureaucracy, but I am still fighting for my dignity and individuality to be upheld. I

question whether there is really choice in accessing care (or indeed in funding care) or does the reality mirror a 'take it or leave it' rhetoric?

The Forgotten Generation

Within the residential context, the social isolation of residents to the outside world reflects a forgotten society. The public and politicians in my city remain unaware or unconcerned with the presence of residential establishments. Rigid systems lead to a sense of powerlessness and loss of control. Availability of staff, increased vulnerability in your living situation, alongside coping with the emotional and psychological effects of moving to a care home, leads to a "wearing down of you as a person". Expectations and self worth and dignity are eroded, and your energy and willingness to challenge and assert your individuality and uniqueness as a person decreases. The alarm bell epitomises the nature of this. Whilst it is the only means to alert someone to your needs, when unable to independently get out of bed, wash or toilet yourself; one has to wait until 'they' are ready to attend to you. Additionally, the uncontrollable noise, emanating from others becomes a constant presence over which one has no control. It is indeed the right of that individual to create noise, for example the TV on very loud and doors left open. This noise intrudes on your personal space and can become unbearable.

Moreover, alongside these challenges of the residential world, accessing services available to those outside of residential care becomes a challenge. Health and social care practitioners, including GP's, and social workers, only visit because they have to. My personal experience, at times, is that I am seen as an "inconvenience" within their working day. This further serves to enhance feelings of worthlessness and the right to be considered as an individual.

Count your blessings

I have experienced good relationships with invaluable care workers. These workers have respected my dignity, seen me as a unique individual, and attended to me in a compassionate way. I breathe a sigh of relief on days when these people are assigned to care for me. These are very special people, who are poorly paid and not valued by society. The danger of not being valued by society is a dangerous one, as seen in many serious case reviews (Winterbourne view 2012 etc). The need to know who is on duty is of great importance to me; in particular the right care worker can lessen feelings of fear, vulnerability and powerlessness. Personal care is a term too easily used. It "slips off the tongue" without real consideration of what it means. I am in need of assistance when often my presentation is undignified and embarrassing and I challenge anyone to fully understand without having personally experienced it. However, the ethos of residential care is that I should be grateful that someone is there to provide this, without an understanding of how degrading it is to a person to have an unknown individual complete the most personal care tasks. When I challenge poor care I am viewed as "difficult" or "ungrateful", when all I am fighting for is for my "well-being" (Care Act 2014) to be recognised. The use of agency workers who you have never met and do not know you, reflects the fault of the system that prioritises the number of carers required on a shift, over the quality of care provided. Who provides the care does not seem to matter. This only adds to the negative psychological and emotional impact of residential care; it wears you down. What happens in a care setting matters! Indeed how it happens is even more important.

Conclusion

The Adult Social Care: Quality Matters policy document, published in July 2017, continues to include the need for person-centred care, the need for service users to be involved in the decisions made about them and to ensure their views are heard. Moreover, it includes the need for people's dignity to be upheld, leading to safe and effective services. Indeed, the Care Act Guidance (Department of Health and Social Care 2018, Part 1:1) states "the core purpose of adult care and support is to help people to achieve the outcomes that matter to them in life." The contemporary practice of the 3 conversations model refers to "sticking like glue" when supporting a person through a period of instability (Worcestershire County Council 2019). Clearly, the value of the person is acknowledged and recognised, but this needs to be reflected in service user's experiences, something I will continue to fight for. I believe this can only be achieved by recognition of the skilled work good carers do and by changing societal views to value the lives of those who live in residential care.

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